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Decisions and Delays Within Stroke Patients' Route to the Hospital: A Qualitative Study

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Study objective: We examine acute stroke patients' decisions and delays en route to the hospital after onset of symptoms.

Methods: This was a qualitative study carried out in the West Midlands, United Kingdom. Semistructured interviews were conducted with 30 patients (6 accompanied by partners). Patients were asked about their previous experience of having had a stroke and their initial engagement with health services. "One sheet of paper" and thematic analyses were used.

Results: Three potential types of delay were identified from onset of symptoms to accessing stroke care in the hospital: primary delays caused by lack of recognition of symptoms or not dealing with symptoms immediately, secondary delays caused by initial contact with nonemergency services, and tertiary delays in which health service providers did not interpret the patients' presenting symptoms as suggestive of stroke. The main factors determining the speed of action by patients were the presence and influence of a bystander and the perceived seriousness of symptoms.

Conclusion: Despite campaigns to increase public awareness of stroke symptoms, the behavior of both patients and health service providers apparently led to delays in the recognition of and response to stroke symptoms, potentially reducing access to optimum and timely acute specialist assessment and treatment for acute stroke. [Ann Emerg Med. 2014;■:1-10.]

Please see page XX for the Editor's Capsule Summary of this article.

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INTRODUCTION

Background

Stroke is a leading cause of morbidity and mortality worldwide, with an estimated 5.7 million deaths and approximately 50 million disability-adjusted life years lost every year.¹ Urgent treatment with intravenous thrombolysis using alteplase for acute ischemic stroke can markedly improve patient outcomes for eligible patients. Timely access to therapy depends on patients' and health service providers' recognizing symptoms early, facilitating prompt arrival in the hospital, and accessing specialist assessment and treatment, ideally as soon as possible after symptom onset, and within the "therapeutic window" of 4.5 hours.²⁻⁴

There is wide variation in the proportion of people with symptoms of stroke who contact emergency medical services (EMS) (19% to 58%) as opposed to other health service providers such as family practitioners.⁵⁻⁸ Delays at any stage of the care pathway can have a major influence on

the proportion of patients who receive timely assessment and treatment in the hospital.⁹⁻¹²

Importance

Previous work has shown that individuals who do not call EMS are delayed in arriving at the hospital and has principally considered the way in which recognition of symptoms influences initial help-seeking behavior.¹³⁻¹⁷ Similarly, public health campaigns have concentrated on the recognition of the symptoms of stroke and the importance of promptly calling EMS.¹⁸

In the United Kingdom, as with other health services, patients' first contact with health services can be calling EMS, directly attending the hospital emergency department (ED) (Figure E1, available online at <http://www.annemergmed.com>), or contacting primary care (through a nonemergency telephone triage service or direct contact with a family practice or walk-in center). Subsequent transportation alternatives include ambulance and private or public

Editor's Capsule Summary*What is already known on this topic*

Stroke is a time-dependent condition, but patients and families are sometimes delayed in seeking care.

What question this study addressed

This qualitative study analyzed how 30 patients with acute stroke decided to seek care, how they engaged with the health care system, and what influenced those decisions.

What this study adds to our knowledge

Delays arose from 3 sources: patients' lack of recognition (or perhaps denial) of the significance of their symptoms, a decision to first contact primary rather than emergency medical services care, and lack of recognition of the significance of the presentation by the initial health care providers. Bystander advice was associated with more rapid recognition and care.

How this is relevant to clinical practice

These results suggest that efforts should focus on broader public awareness of critical signs of stroke, and specific directives to engage emergency rather than primary services.

transport. No previous studies have addressed how patients navigate through these multiple options or their experiences when first contact with the health service does not result in immediate transfer to the hospital.

Goals of This Investigation

This study aimed to understand through patients' narratives how decisions are made and delays occur en route to the hospital after the onset of stroke symptoms.

MATERIALS AND METHODS**Study Design and Setting**

This qualitative study was part of a larger mixed program of work that recruited patients with stroke who attended 2 urban hospitals within the West Midlands, United Kingdom,¹⁹ with an ethnically diverse catchment population. Both participating hospital trusts offered a 24-hour thrombolysis service, 7 days a week, but in the case of the second trust, this was achieved by combining an "in hours" service, 9 AM to 5 PM, Monday to Friday in the lead hospital, with out-of-hours care at a separate site. A summary of the patient pathway for acute stroke in the

United Kingdom is detailed in [Figure E1](#) (available online at <http://www.annemergmed.com>). At the study, a 4.5-hour maximum window for thrombolysis was in operation. The prevalence of stroke in West Midlands is estimated to be approximately 17 per 1,000 population, similar to national rates.²⁰

Selection of Participants

Participants were purposively recruited on the basis of their route to the hospital and demographic characteristics (sex, age, and ethnicity). Patients who had experienced a stroke within the last 6 months were contacted either directly on the ward or by invitation letter postdischarge from the hospital. Patients were excluded if they had previously stated they did not want to be contacted about the interview study, required a consultant to consent for them, were non-English speakers, or were unable to communicate (eg, severe aphasia). Participant characteristics were collected from the patients or their hospital records.

After informed consent, semistructured interviews with a topic guide ([Appendix E1](#), available online at <http://www.annemergmed.com>) were conducted by 4 female interviewers, each trained in qualitative methods, who were not part of the patients' health care team. The topic guide was developed by the study team, with the first draft based on information gained from reviewing the literature, but then was influenced by data from the interviews; for example, asking participants specifically about awareness of a stroke campaign, as well as generally about their previous knowledge of stroke. When present, partners were invited to participate to fill in any gaps in patients' accounts, with the emphasis of the interview on patients' accounts. Patients were asked about their experience of having an acute stroke and of health services, with particular emphasis on their route to the hospital.

Patients chose their interview setting and were interviewed once, with the exception of 1 participant who received a follow-up interview. Interviews were conducted between January 2011 and July 2013, and ranged from 15 minutes to 2 hours in length, mean 46 minutes. Interviews were audiorecorded and transcribed verbatim. Field notes were recorded at the end of each interview and similarly transcribed.

Primary Data Analysis

Transcripts were checked for completeness and accuracy. NVivo 9 (QSR International)²¹ was used to manage the data. Researchers took an interpretive approach to data analysis, acknowledging that patients were recalling their perspectives of their experience rather than the "empirical

truth,” and with the knowledge that they had experienced a stroke.

Initial analysis was conducted with the “1 sheet of paper” method, where for the first interviews all the points raised about patients' route to the hospital within each interview were noted on a sheet of paper, along with the participants' pseudonym.²² This allowed the points to be grouped and summarized and provide a basis for development of the main themes. It gave insight into variation in responses between interviews and how themes linked.

This 1 sheet of paper method provided the structure for further analysis, onto which the rest of the interview data were added as they were collected. A constant comparison analysis approach was taken, in which sections of data were compared to establish differences and similarities.²³ Analysis was conducted at the individual level and by the initial health service provider contacted. This provided the components of the 3 themes outlined below. To ensure analytic rigor, both R.M.M. and S.B. coded and double coded a subset of interviews, meeting regularly to compare findings and resolve differences through discussion.

Furthermore, R.M.M. and R.J.M. reviewed summary data, discussed it in light of the literature and clinical experience, and referred to the original transcripts to ensure that emerging interpretation remained grounded in the original data, and through this process the final delay categorization was reached. Interviews ceased when data saturation was reached; that is, when no new theme emerged. This happened after 30 interviews had been carried out, which is consistent with the recommended sample size to allow saturation to be achieved in this type of study.^{24,25}

Participants have been sent a lay summary of all study findings, but member checking, either of the study or their individual transcripts, has not been conducted. Quotations give patients' sex, age, and initial service contacted.

The London-Queen Square Research Ethics Committee (09/H0716/71) approved this study.

RESULTS

Characteristics of Study Subjects

Thirty stroke patients were interviewed, including 6 with their partner. They all lived in an urban area, and the majority of interviewees were men ($n=22$), were white British ($n=26$), were younger than 65 years ($n=18$), and experienced their strokes at home ($n=25$) (Table). More than half ($n=18$) contacted 1 service before arriving at the ED and then stroke treatment; the remainder had more circuitous routes. Less than half ($n=15$) arrived within 3

Table. Participant characteristics.

Characteristic	Interviewees ($n=30$)
Sex	
Female	8
Age, y	
Range	32–85
>65	18
Ethnicity	
White British	26
Indian	1
Pakistani	3
Socioeconomic status	
Index of multiple deprivation 2007, median, interquartile range	40.4, 34.1
Time of interview poststroke	
Range	5 days–9 mo
Up to 3 months poststroke	20
Location of stroke event	
Home	25
Work	3
Other: supermarket, in car	2
Time from symptom onset to presentation at hospital, hours	
≤3	15
>3	4
Unknown onset time (as recorded in hospital records)	11
Delay to contacting initial health service (primary delay)	
Delayed contacting health service	17
Immediately contacted service	13
Initial health service contacted (secondary delay)	
EMS	16
Made own way to hospital	9
Walk-in center/family practice	3
Nonemergency telephone triage service	2
No. services contacted before arriving at the ED and then stroke treatment	
1	18
≥2	12
At least 1 service provider en route to hospital did not recognize the seriousness of the symptoms and directed to an inappropriate or no service (tertiary delay)	
Yes	5
No	25

hours of the onset of the symptoms, but many ($n=11$) had no onset time recorded in their hospital records.

Main Results

Delays en route to the hospital were defined at 3 levels on the acute stroke pathway: (1) primary delays, which included a lack of recognition of stroke or serious symptoms or lack of response to these symptoms; (2) secondary delays, which included initial contact with nonemergency health services (eg, making an appointment with the family practitioner rather than calling EMS); and (3) tertiary delays, which meant patients' presenting symptoms were not initially interpreted as

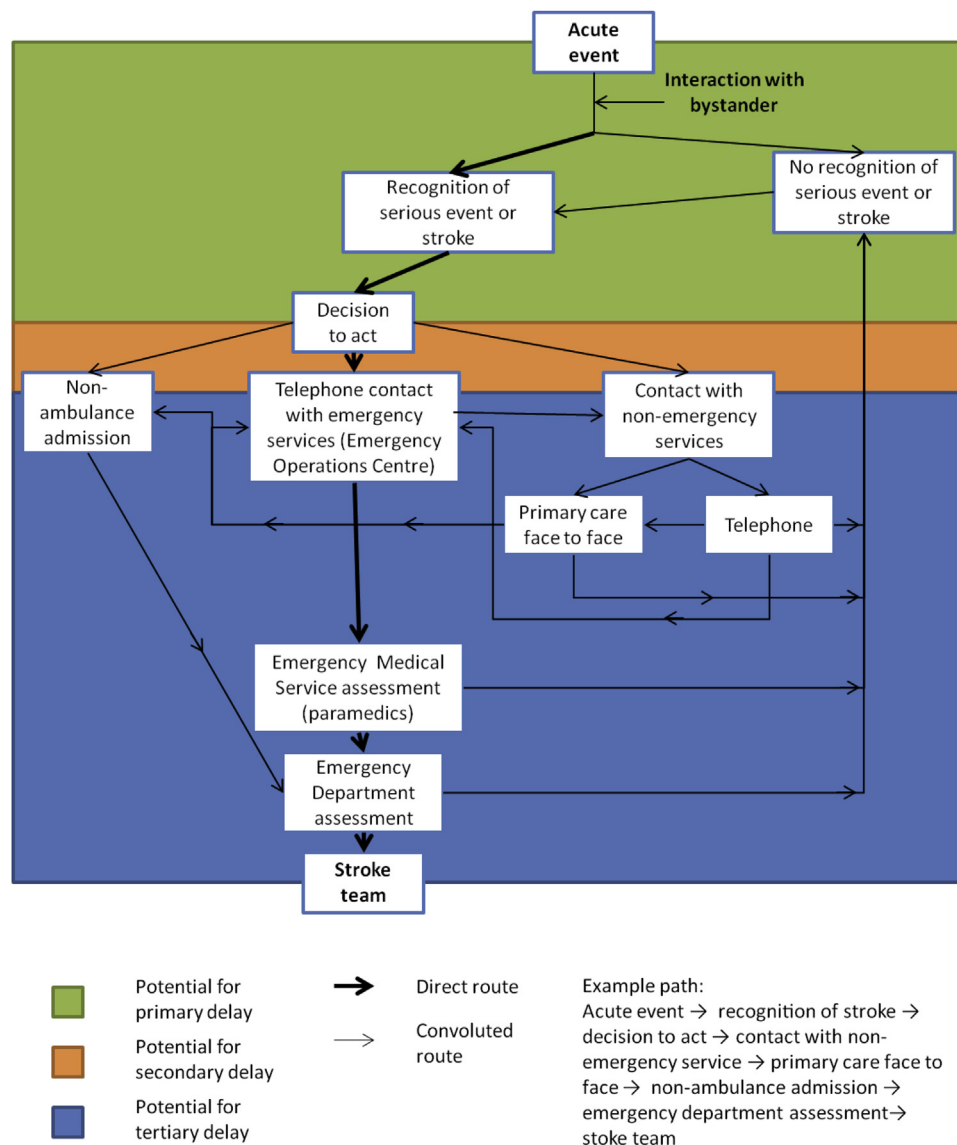


Figure. Flowchart showing different responses to onset of stroke symptoms.

indicating a stroke by the health service provider (eg, a family practitioner, EMS).

Patients could potentially be subject to 1, 2, or all 3 levels of delay. The flow of decisions from onset of symptoms until hospital arrival is summarized in the [Figure](#).

For primary delays, the lack of recognition of stroke or lack of response to those symptoms was influenced by bystanders and the perceived seriousness of those symptoms. Bystanders (family members, friends, or work colleagues) were frequently mentioned in accounts of the route to treatment. They became involved because they were present at the time, the patient sought them out, the patient saw them by chance, or they recognized symptoms that the patient was unaware of.

Patients frequently (n=11) reported seeking advice or help from friends, family, or others present at the time to confirm that something was wrong and determine necessary action.

"I managed to get on the side of the bed and lift myself up and then I just fell back and I managed to ring.... I rang my brother." (Man, aged 32 years, walked into the ED.)

In other instances (n=12), patients were not aware or resisted the idea that something was seriously wrong, and it took another bystanders to persuade or "force them" into seeking help.

"I said, 'No, no, I'm all right. I'm all right.' And they sort of bullied me into taking me to [hospital name].... I was angry because I mean the girls had persuaded me, or forced me to go

into hospital and I didn't want to go into hospital, let alone be kept overnight." (Man, aged 65 years, walked into the ED.)

Several factors affected whether bystanders were able to influence the patient to seek help: the patient's relationship with them, whether they were seen to have some "medical knowledge," their perception of the patient's ability to make a decision at that time, and their level of proactiveness in the situation.

In a minority of accounts (n=8), a bystander delayed the help-seeking process. Implicit reasons for this were not wanting to take responsibility for the decision but rather contacting someone else who they viewed was able to do it (for example, calling the patient's daughter rather than EMS directly); perceiving the situation to be less urgent or serious than the patient did; or misinterpreting the symptoms and thinking the situation was not serious (for example, thinking the patient was intoxicated).

Some patients were alone at symptom onset (n=5). Depending on the severity of symptoms, such individuals were able to decide whether they wanted to seek help themselves or wait for someone else to assist. They may not have had the physical or practical ability or mental clarity to contact services and communicate their symptoms on their own.

"I was putting the groceries away and I fell.... He [brother] came [to visit] unexpectedly.... [O]therwise I would have lain there, you know, for a long time." (Woman, aged 85 years, called EMS.)

Patients were influenced in their actions by their perception of the seriousness of the symptoms. Moderate symptoms were described as feeling weird or dizzy or having a headache or migraine, whereas patients who reported limb numbness or facial droop often reported that their symptoms were serious. People who believed the symptoms were serious called EMS, made their own way to hospital, or telephoned a nonemergency telephone triage service to confirm the significance.

"He said the room was spinning round, and I said, well, 'Do you want me to call the doctor?' 'No' was his answer again...and on the third occasion, when he does do it again, he comes back into the room, tries to sit on the bed and, whether he didn't see the bed, or he thought it was there, and the next thing, he's on the floor.... I said, 'This is ridiculous; I'm going to call the doctor.'" (Man's wife, aged 66 years, used a nonemergency telephone triage service.)

Symptoms were not perceived to be serious if patients thought they could self-medicate (for example, go to bed and receive painkillers); if they could relate it to a previous illness that had not been serious; if they were in denial; or if their judgment had been clouded. Some younger patients (<65 years) reported that they thought they were too

young to have a stroke; therefore, their symptoms could be attributed to something less serious, ie, a migraine.

"I came downstairs and I was met with [work colleagues], who said I'd got a migraine. I've never had a migraine before and so I thought, you know, that that's pretty plausible and I'll just go home." (Man, aged 37 years, walked into the ED.)

Secondary delays, initial contact with a nonemergency health service, were influenced by uncertainty about the seriousness of the symptoms, previous hospital experience, and ease of access to services.

Ideally, patients would contact EMS to take them immediately to the hospital, but some arranged private transportation.²⁶ A minority (n=5) of patients initially contacted non-EMS health service providers, who were unable to treat or provide direct access to treatment for symptoms of stroke: nonemergency telephone triage service, family practice, and walk-in center. Non-EMS providers could refer to a more appropriate service.

The bystander quoted below contacted the nonemergency telephone triage service to confirm the seriousness of the symptoms, which resulted in a physician callback, delaying the EMS call. Similarly, access to family practice could result in an initial delay if stroke symptoms were not recognized when an appointment was booked.

"So I called national health helpline; we had a good discussion.... They said they would ring us back, which they did, and a doctor spoke to me and said, 'Yes, call an ambulance straightaway,' which we did." (Man's wife, aged 66 years, used nonemergency telephone triage service.)

Previous experience of hospitalization could affect desire to attend. One patient had reported a good hospital experience, which reinforced his choice to travel to the hospital; however, another reported a particularly unpleasant recent stroke experience, which contributed to her convoluted route: after initially calling EMS, she did not use the ambulance that arrived but rather waited a day before going to her family practitioner.

"We got the ambulance again on Sunday night, and the driver said, 'Oh, how are you feeling [patients' name]? You know, you're looking all right,' and I said, 'Yes, I feel not too bad actually,' and I did not want to go and spend another night in that horrible ward, so I said I'd stay at home and see." (Woman, aged 77 years, called EMS.)

One patient delayed accessing services because he already had a family practice appointment booked. Other patients gave specific reasons for making their own way to the hospital as opposed to calling EMS: going by car would be faster, and it would be easier because there was a car on hand. Some had not considered calling EMS, whereas others were concerned about wasting health service resources.

Tertiary delays, in which health care providers did not initially interpret the patient's presenting symptoms as serious or suggestive of stroke, could occur within the emergency health service or within primary care and result in multiple providers being involved before the patient received appropriate treatment.

Most patients (n=25) contacted EMS or made their own way to the ED, which should have led to urgent treatment. In a minority of cases (n=3), participants reported that EMS providers did not interpret their presenting symptoms as serious or suggestive of stroke. As noted earlier, there was one instance when an ambulance crew was involved in the patient's decision not to go to the hospital. Two patients reported that the EMS operations center suggested they contact their family practice. These instances were unusual: one patient was ill on New Year's Eve and 1 had stated to the EMS emergency operations center that he was an alcoholic (in addition to suggesting that he was having a stroke). Furthermore, conveying information over the telephone potentially leads to poor understanding of symptoms.

"Then I rang the 999 [EMS] straightaway, which in turn put me onto the ambulance station, who told me to go and ring the mobile doctor, which I contacted. He said, 'Well, he's on his way, but he won't be coming for some time yet and it could be 2 hours.'" (Woman's husband, aged 78 years, called EMS.)

Two men reported receiving a misdiagnosis in the ED and leaving the hospital rather than being admitted. Hospital staff had thought it was a less serious diagnosis, ie, virus. Both returned to the ED later. As discussed below, although the patient thought his symptoms were serious, he was concerned about being a "bad patient" and questioning the physician, and this created reluctance (which he overcame) to seek further care.

"It was playing with my head because I didn't want to waste anybody's time or thinking that I'm like a hypochondriac: 'You know this guy: he's coming but he's not letting the medication sort of take its course or anything,' but it wasn't improving and I was getting worse...." (Man, aged 39 years, called EMS.)

Although some primary care physicians immediately called EMS on recognizing individuals with symptoms of stroke, others did not organize an emergency admission. Patients who did not get a sense of urgency from primary care could delay further. The patient below refused the offer of an ambulance and delayed her hospital attendance to cancel her exercise class. Her example is of both a primary and tertiary delay because she deviated from her advised immediate hospital attendance, earlier reporting she did not perceive the symptoms to be serious or urgent, and

is also a tertiary delay because the nurse involved did not insist on using EMS.

"[Nurse] said, 'I'm going to write a note and I'm going to phone them and say you're on your way.' I said, 'But I've got to let them know at tai chi because they'll wonder what's happening and it's only round the corner at [name of road].' She says, 'You need to go now.' I said, 'Oh, all right.'... And then when I got outside I thought I've got to let them know at tai chi, so I walked from [name of walk-in center] round [to tai chi class]." (Woman, aged 57 years, used walk-in center.)

Three patients attended the family practitioner between 1 day and 2 weeks after the initial stroke. This delay might have influenced the family practitioner's decision not to insist on EMS use. In one case, the family practitioner had concerns about the patient's general health and thus advised against hospital attendance in case the patient contracted an infection. One was given the choice of an ambulance or to make his own way to the hospital; he chose to use public transport. The other patient was told to go to the hospital and was asked whether he was able to get there. However, the patient's means of transport required him to walk home and ask his neighbor to drive him to the hospital. He attributes this decision to use private transport as the best use of resources because of lack of certainty over his diagnosis. From his account, it would appear that he did not disclose to the family practitioner the convoluted route that he would take to hospital.

"She [family practitioner] wrote me a letter and sent me straight down to the hospital....

The doctor didn't suggest calling an ambulance?

No, because I don't think she was sure that I'd actually had a stroke. I'm sure she suspected; she did ask me did I have somebody with me, and did I have a means to get to the hospital, and I had, you know [walking home with his wife and neighbor driving him]. Ambulances are for people who really need them." (Man, aged 51 years, used family practice.)

Whenever services redirected, the decision on how to proceed depended on patient or bystander response. Sometimes this led to a more convoluted route to the hospital, with 2 or more services contacted (either the same or a different service) before arrival at the ED.

LIMITATIONS

Patients who received a final diagnosis of stroke were purposively recruited according to the initial health service provider contacted on onset of stroke symptoms (identified during data collection for the larger observational study).¹⁹ However, despite purposive mailings, it was difficult to

recruit individuals who used non-EMS routes, and recruitment depended on patients' responding to written requests for participation. Similarly, fewer women agreed to be interviewed, and patients who required consultant consent, could not speak English, had severe aphasia, or were too ill or had died were excluded from the study, so their perspectives are not represented. Because the sample was restricted to patients with a final diagnosis of stroke, excluding those with symptoms of stroke but a different diagnosis, it is not possible to comment on the implications for their treatment, in which a less urgent response may be more appropriate. Similarly, patients with more severe stroke were less likely to be included and may have had different experiences. It is also possible that patients with less positive health service experiences were more likely to agree to be interviewed because they wanted to be able to tell their story.

Although patients were recruited from a limited sample of 2 hospitals, the local stroke services available were reflective of current national practice.²⁷ Health care organization varies from country to country, but the ability to call an ambulance or instead contact another health care provider is common to most Western countries, and hence the delays considered here are widely relevant, albeit potentially from differing providers in different countries. For example, a health maintenance organization might require initial contact with a triage service in some circumstances, potentially leading to delays should a patient or triage officer not recognize symptoms immediately.

A further limitation was that some patients had difficulty recalling the details of their route to the hospital. Reasons for this included conducting the interview several weeks after the event and patients being asked about a time when they were not well and hence had impaired recollection. Furthermore, by the time of interview, participants had received a diagnosis of stroke, and this knowledge may have influenced their perceptions of their earlier memories. The presence of partners in 6 of the interviews may have influenced how patients presented their narratives²⁸; however, it assisted in filling any gaps in patients' memories, and their presence was appreciated in terms of moral support.²⁹ Furthermore, in the case of all partners, they had been present in the patients' route to the hospital.

DISCUSSION

Patients experienced a range of out-of-hospital delays: (1) primary delays because of lack of stroke recognition or appropriate response to them; (2) secondary delays because of initially contacting a nonemergency health service; and (3) tertiary delays, in which the health service did not

recognize the stroke. Key to patient decisionmaking and primary and secondary delays were the presence and influence of significant bystanders, who could expedite or delay access to treatment. Decisions to choose a certain route were influenced by the perception of the seriousness of symptoms, previous hospital experience, and ease of access to services. Tertiary delays were influenced by whether the health service provider interpreted the patient's presenting symptoms as serious or suggestive of stroke.

Previous studies have focused on primary patient-related delays slowing down stroke patients' route to the hospital.^{16,17} The present study highlights that delays can occur on a number of additional levels, including secondary delays caused by initial misdirection and tertiary delays related to the health service. Even when patients reacted immediately and contacted appropriate services, misdirection by health service providers had significant influence. Previous studies have noted that some family practices can delay patients' arrival to the hospital by organizing a home visit,³⁰ by not arranging for the patient to be taken to the hospital, or by not stressing the urgency of arriving at one.¹⁵ This study has found additional sources of delay farther along the stroke pathway, up to and including the ED.

This study highlighted the importance of bystanders in primary and secondary decisions in the route to the hospital, mostly in a positive way, although some of our patients actively resisted bystanders' making decisions. Mackintosh et al¹⁵ reported patients using bystanders to avoid taking responsibility and generally causing delay. They perceived bystanders contacting EMS so that the responsibility was removed from them. Molocziej et al,¹⁷ Jones et al,¹⁶ and Harrison et al³⁰ also reported negative instances.

The present study highlights the range and importance of patients' perceptions of symptoms. Mackintosh et al¹⁵ reported a range of perceptions, with some patients ignoring symptoms in the hope that they would "go away" and finding that patients whose symptom onset was not significant might delay seeking attention. Molocziej et al¹⁷ emphasized the importance of feeling pain and how the lack of this in most stroke patients could result in initial contact with nonemergency services. Quantitative studies have linked neurologic severity with delay to arriving at the hospital.^{13,14,31,32}

Our findings and the stroke-specific literature have striking similarities to the findings of studies during several decades of help-seeking behavior among people experiencing acute myocardial infarction. For example, Kirchberger et al³³ found misinterpretation of symptoms of heart attack to be associated with delaying the call for help.

Dubayova et al³⁴ reported from their systematic review that intensity of fear was associated with earlier help-seeking. Classic studies from Nottingham, United Kingdom,³⁵ and Rotterdam, the Netherlands³⁶ reported significantly longer delays in hospitalization and initiation of reperfusion therapies when patients sought advice from their primary care physician rather than calling an ambulance.

The decision by health service providers on how best to respond to initial patient presentation is crucial and is often made by receptionists or ambulance dispatchers. The present study highlights the importance of nonemergency services in directing patients toward emergency care in acute stroke. Family practitioners should emphasize the urgency of ED attendance and arrange ambulance transportation when referring patients with suspected stroke to the hospital. Warning hospitals or providing a patient referral letter to expedite the patient journey to the hospital after initial secondary delays (and in some cases primary delays) may not be as effective as ambulance alerting.^{12,37,38} Further training in stroke recognition should be considered for nonclinically staffed, nonemergency telephone services to avoid secondary delays' being compounded, leading to worse outcomes. This is particularly important, given that only 3% of EMS calls for stroke include more than 1 facial asymmetry, arm weakness, or speech disturbance (FAST) symptom,³⁹ although a balance needs to be struck to ensure that service providers do not become overly risk averse and send too many patients to emergency care, which could overload the system. Patients may not be the best judges of the seriousness of their symptoms; therefore, bystanders can be extremely important in their seeking care. Campaigns could encourage members of the public to assist when symptoms of stroke are suspected. Furthermore, current campaigns aimed at ensuring the correct use of EMS must be cautious not to dissuade people from seeking emergency care if they are uncertain whether their symptoms are serious. Members of the public should not be expected to always make the best decision during a medical crisis; rather, the health service organization should direct them appropriately, whatever the initial point of contact.⁴⁰

Limited data from a recent systematic review of UK literature on awareness of and response to stroke symptoms revealed a good level of knowledge of the 2 commonest stroke symptoms (unilateral weakness and speech disturbance) and of the need for an emergency response among the general public and at-risk patients. Despite this, less than half of patients recognized they had experienced a stroke. Symptom recognition did not reduce time to presentation. For the majority of patients, the first point of

contact for medical assistance was a primary care physician.⁴¹

The English mass media campaign Act FAST aimed to raise stroke awareness and the need to call emergency services at the onset of suspected stroke. Although some stroke patients and witnesses reported that the campaign affected their stroke recognition and response, the majority reported no effect. Clinicians have often perceived campaign success in raising stroke awareness, but few have thought it would change response behaviors.⁴² These findings were confirmed in a subsequent systematic review by the same research group.⁴³

In summary, there are several points en route to the hospital at which patients or health service providers can potentially delay access, which will affect patients' ability to receive timely assessment and treatment. Patients have described delays caused by both themselves and health professionals who responded to their initial presentation. Bystanders appear to be important in the decisionmaking processes both in terms of initiating action in the face of symptoms of stroke and in deciding what action to take. Future stroke public awareness campaigns should encourage members of the public to assist where signs of stroke are recognized and direct patients to emergency services. Potential delays caused by health professionals could be reduced through training for first-point-of-contact health service providers (family practice receptionists and EMS dispatchers) to assist them in recognizing symptoms and ensuring that illnesses of patients with possible stroke are treated as emergencies.

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APPENDIX

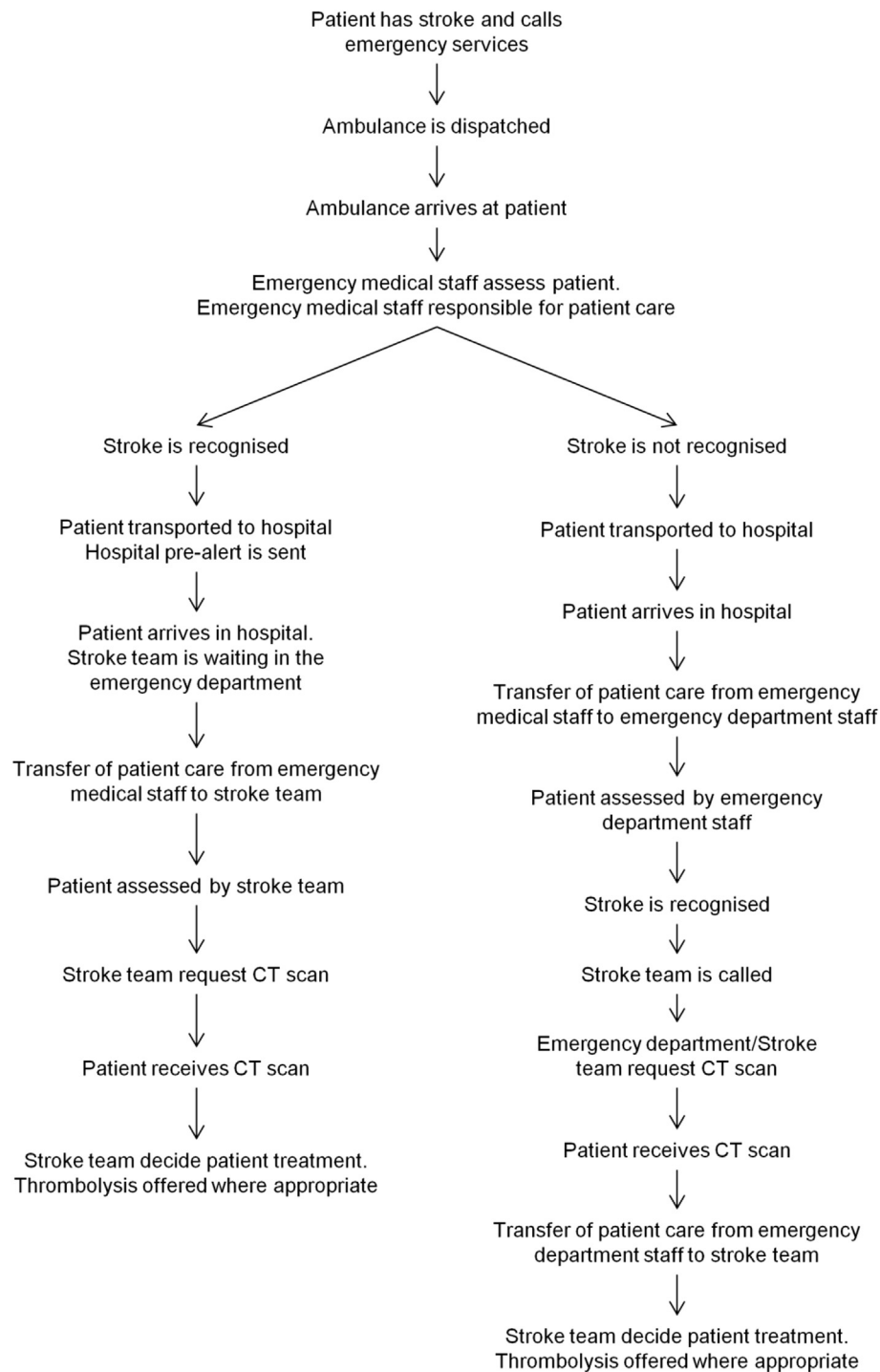


Figure E1. Patient pathway for acute stroke in UK hospitals offering a stroke service 24 hours a day, 7 days a week, in instances in which patients arrive by ambulance. Reproduced from Sheppard et al¹ with permission from BMJ Publishing Group Ltd.

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APPENDIX E1. Study topic guide

COLLABORATIONS FOR LEADERSHIP IN APPLIED HEALTH RESEARCH AND CARE

Research Theme 7: Optimization of the Management of Stroke and Transient Ischemic Attack

Interview topic guide

Interviewer name

Site

Study ID No.

Date

PREAMBLE

Introduction: Self, including position and attachment to the hospital or environment. Reiterate that we are researchers for the University of Birmingham and not the clinical team. Therefore, we may ask questions that could be sought in the patients' medical notes.

Explain that the objective of the research is to interview patients to find out their views and experiences after a stroke or TIA ("ministroke"). In particular, look for information about the way health care services were provided for them and their experience of what a stroke or TIA means.

The patient is to be reminded that the research is voluntary, and if they decide not to take part, their medical care will not be affected.

Ensure that the patient or patient representative has read and understands the patient information sheet. Ask whether there are any further questions.

Inform the patient of the order of the questions. Identify that they will follow 3 main aspects within stroke care: admission, preadmission, and poststroke care. The researcher will ask approximately 13 questions within these 3 areas and may use miniquestions or prompts.

The interview is likely to take approximately 20 to 40 minutes.

Identify that the patient or representative has the opportunity to pause or stop the interview at any time.

The interviewer may need to repeat a summary of certain aspects of the preamble, depending on the patients' cognition.

Explain that the interviewers may look down at the sheet from time to time to remind themselves of the key questions and that this does not mean they are uninterested.

TOPIC GUIDE FOR PATIENTS' PERSPECTIVES IN A HOSPITAL SETTING

Section 1: Preadmission

How are you feeling today? (Optional)

Better or worse than yesterday?

Can you tell me what happened that brought you into the hospital?

Emphasize route and how they got there.

Paramedic experience (if applicable).

Before you came into the hospital, what was the last thing you remember?

Problem, symptoms

What did you do when you were aware of these symptoms?

Ignored the symptoms or sought medical advice (NHS direct, or physician or nurse), or talked to a family member or used the Internet?

Did somebody else notice the symptoms?

Aware of FAST test or campaign?

What did you think was wrong?

How did you feel at this time? Not had time to consider feelings, concerned, not worried.

Has something similar ever happened before?

What emotions did you feel at this time?

Relieved, nervous, uncertain, surprised, frightened, isolated, or supported.

What were your main concerns? Family commitments, work, pets, other responsibilities, long-term health implications?

Did you have to make any arrangements before seeking medical advice?

Pets, children, work, other responsibilities?

Section 2: Admission

How long have you been here?

In this hospital or ward?

Can you tell me what happened when you actually came into the hospital?

Who accompanied you to the hospital?

Did you wait in A & E; see the physician; have any tests, ie, thrombolysis or scans; go straight to the ward?

How did you find the information about what was going on? Did you understand what was happening?

How did you find the care given?

Was there anything you thought could have been done better or anything you would have liked but that did not happen?

Medical, nursing, physio care? Expertise, communication, timing of treatment? How would you describe your hospital stay?

Is there anything about your hospital stay that especially pleased or upset you?

What do you understand is the next step in your care?

Further tests, physio, social services, discharge.

Section 3: Poststroke Care

How do you think this could be improved?

Personalized care, support group information, more lifestyle information, more information?

Can you describe what effect the stroke has had on your life and relationships?

How else did your life change after the stroke? Partner, children, work, home, pets, friendships.

Overall how do you think the stroke service could be improved? *(Of what you have experienced so far.)*

CONCLUDING REMARKS

Any questions about the research study?

Identify that we may ask for a further follow-up interviews to examine patients' opinions and experiences throughout different periods of their stroke care if the patient is happy to be reapproached.

Ensure that the respondent is happy with the way the interview has been conducted.

Remind the patient that all information will be treated in confidence.

Ask if willing to have a follow-up interview.